

Summary of ECD General Alliance Internet Chat

16 July 2016

5 Attendees

- The Chat started with a US member saying how sorry she felt about the recent events in France. She said that she and her husband have decided not to go to the conference in Paris after all.
- A member who has had a lot of problems with her insurance company (authorisation of a PET scan), said that she is going back to Dr. Diamond in August for an appointment and more scans. The doctor's assistant has written saying that if insurance won't cover the scan costs, then Memorial Sloan Kettering (MSK) will. She thinks that the insurance covered about half of the cost of the PET on the last occasion. She has an attorney involved trying to sort it all out. She is now on 3 vemurafenib (V) a day. She is still dizzy and her joints hurt, different ones on different days. The only pain reliever she takes is an occasional Tylenol or Advil. In The Grand Tetons, where she has been with her sisters, she probably walked 3 miles a day. Now she is at the beach with more family, and will get a workout in the sand and ocean. She gets covered up and uses sun screen.
- A member who had to stop V because his liver enzymes became raised, has done very well on Dabrafenib (D). It was suggested that maybe she should seek a change. She thinks that Dr. Diamond will switch her.
- A member who has been on V and is now in remission on a low dose, said that he is considering switching to D for maintenance therapy, but he thinks that it is hard to get this authorized unless someone is enrolled in a study. Patients who have previously taken vemurafenib do not normally qualify for a Dabrafenib study.
- A member has just had diabetes insipidus diagnosed by his family doctor, having had blood and urine tests done. He comes from France, and is waiting to get an appointment with Professor Haroche. He had been told by his rheumatologist that Professor Haroche would contact him, but he hasn't been in touch yet.
- A member said that he had the impression that he had "breast cysts". Another member said that she had been told by a doctor at NIH that breast issues were rare with ECD, but they may be histiocytic lesions.
- A member with BRAF negative ECD said that she had started taking trametenib that day. Dr. Diamond and her local doctor work together. Her doctor wanted her to start with 1 mg 3 times a week and just work herself up weekly, until she got to 2 mg. But when she received the pills, they were not scored and she was advised by the pharmacist not to cut the pills in half, so she took 2 mg.
Her eyes have been awful recently and she has had some bleeding in the back of left eye. She had a shot of Avastin on the previous day and the eye specialist is following up in 2 weeks. Her ECD is in the orbits and choroid layer of the eye, and bones. Her blood work is fine (Alk. Phos was a bit elevated and her CD4 count is low as it has been ever since she had chemo 4 years ago!!).
- A member said that she had just noticed a big bruise. She is not taking any blood thinners and her platelet levels have been fine. She is having more blood work on July 25. It was said that maybe some of the drugs that she takes thin the blood too, so there is bleeding and the blood does not clot as normal.

Her ECD was first discovered when she was having vision problems. She had an MRI of her brain and orbits. Her skull "just lit up" and they took a biopsy from the right frontal part of her skull. The bone problems came later. At the time they said it was Rosai-Dorfman disease (RDD) and not ECD. They knew it was histiocytosis but didn't know what kind. A doctor in Houston diagnosed it as RDD. NIH also took biopsy samples and also said that it was probably RDD. Later, they changed the diagnosis to ECD. She has characteristics of both RDD and ECD which has made things very complicated.

- A member has moved back to MN from San Diego. He doesn't think that he will return to Dr Diamond for a combination of reasons (insurance, money, and time).
He was asked about his use of V. He had started on the highest dose of 8 pills a day, but only for 5 days! He had a very quick response to the drug. His eye issues were taken care of immediately from a clinical perspective. The lesions are not totally gone (and may never be) but he is ok with that, as long as they are inactive.
Before he had a biopsy, he had been diagnosed with lymphoma. He then had a biopsy of tissue behind his left eye at Mayo by Dr. James Garrity. Probably there are only a handful of doctors in the world that could have done the surgery! His scans had already been sent to Dr. Garrity. The member was concerned that he wouldn't be accepted as a patient. He did the surgery one week after getting the scans. The biopsy confirmed ECD, although the doctor knew that ECD would be the diagnosis, before the member even got to Mayo!
- Three members said that they have the sensation of having sand in their eyes. One said that a lot of the time this is due to poor fluid circulation.
- A member who has been on V for 7 months was seen by 2 doctors on Wednesday the previous week. One at 7:30 am and the last one not until 5 pm (a long day!!). They still think that he is doing well. He currently has some trouble with a sore cyst in the skin of his back.
- Final words of wisdom (not from me, from another member!); "I often think that I'm focusing too much on ECD and forgetting that in this crazy world, and with all the other diseases/accidents that could happen, the chance that I would succumb to ECD is not great".